

IX International GSDs Congress

PROGRAM FOR MUSCULAR AND HEPATIC GSDs



Fuengirola, Málaga
10 – 13 October 2018

Hotel IPV Palace
Km 207 A-7
29640 Fuengirola, Málaga

Wednesday 10 October

First day of evaluation and counselling to patients

16:00-19:00 Evaluation and counselling to **Pompe** disease patients by the team of **Dr. Barry Byrne** (University of Florida)

Thursday 11 October

Second day of evaluation and counselling to patients

09:00-19:00 Evaluation and counselling to **Pompe** disease patients by the team of **Dr. Barry Byrne** (University of Florida)

Friday 12 October

Third day of evaluation and counselling to patients

09:00-19:00 Evaluation and counselling to **Pompe** disease patients by the team of **Dr. Barry Byrne** (University of Florida)

17:45-19:30 Physical Training to **McArdle** patients by **Dr. Alfredo Santalla** (Universidad Pablo de Olavide) and **Dr. Ignacio Ara** (Universidad de Castilla-La Mancha)

Activities of the IX Congress

Main Room

15:30-16:00 **Reception and delivery of documentation and badge**

16:00- 16:30 **Opening acts**
President of the AEEG, President of Association of Glucolatino Spain and representative of Unicaja Foundation and representative of FEDER

16:30-17:30 **Presentation:** Introduction: Benefits of physical activity throughout the life cycle in patients with **McArdle disease** by **Dr. Ignacio Ara** (Universidad de Castilla-La Mancha)

17:30-18:30 **Presentation:** Precision Medicine for Pompe Disease: Next Generation Therapy by **Dr. Barry Byrne** (University of Florida)

18:30-19:45 **Presentation:** New tools for monitoring and treating Pompe disease by **Dr. Jordi Díaz** (Servicio Neurología Hospital Sant Pau; Barcelona)

19:45-21:00 Presentation on gene therapy for **GSD Type I and other hepatic GSDs** by **Dr. David Weinstein** (U. Conn Health, Connecticut Children's Medical Center)

Multipurpose Room

16:30-18:15 Evaluations to Hepatic GSD, type 1B patients

18:15-19:45 Evaluations to Hepatic GSD, type 1A patients

19:45-20:30 **Presentation:** Advice on nutrition in McArdle disease by **Dr. Alfredo Santalla** (Universidad Pablo de Olavide)

20:30-21:00 Natural isotonic design workshop for **McArdle disease**

21:00 - 22:30 **Dinner**

Saturday 13 October

Fourth day of evaluation and counselling to patients

- 09:00 - 20:00** Evaluation and counselling to **Pompe** disease patients by the team of **Dr. Barry Byrne** (University of Florida)
- 09:00 - 14:00** Physical Training to **McArdle** patients by **Dr. Alfredo Santalla** (Universidad Pablo de Olavide) and **Dr. Ignacio Ara** (Universidad de Castilla-La Mancha)

Activities of the IX Congress

Main Room

- 9:00-9:45** **Presentation:** Pathophysiology and therapeutic developments for Pompe disease by **Dr. Marie-Anne Colle** (National Veterinary School, Agribusiness and Food Nantes-Atlantique, France)
- 9:45–10:30** **Presentation:** Pitfalls and pathways to diagnosis of Pompe disease by **Dr. John Vissing** (Director, Copenhagen Neuromuscular Center)
- 10:30–11:30** Presentation on **Hepatic GSDs** disease by **Dr. David Weinstein** (U. Conn Health, Connecticut Children's Medical Center)

Multipurpose Room

- 9:00–9:45** **Presentation:** Liver GSDs and sports by **Dr. Ulrike Steuerwald** (UConn Health, Connecticut Children's Medical Center)
- 9:45–10:30** Presentation on clinical aspects of **Hepatic GSDs** disease by **Dr. Nerea López** (Catalan Health Service)
- 10:30–11:00** Presentation on Juvenile onset of **Pompe** disease in Spain: conclusions and challenges by **Dr. Miriam Ley** (Hospital Puerta del Mar, Cádiz)
- 11:00-11:30** Presentation on **Pompe** disease on the current state of knowledge and future perspectives on the topic of muscle regeneration by **Dr. Manuel Lorente** (Andalusian Health Service, Granada) and María Berrio Miranda

11:30 - 12:00 **Coffee break**

Main Room

- 12:00-13:00** Presentation on clinical management of **Hepatic GSD** disease by **Dr. Ana Estella** (U. Conn Health, Connecticut Children's Medical Center)
- 13:00-14:00** Presentation on latest developments for **Hepatic GSD** disease by **Dr. Kathy Dalhberg** (U. Conn Health, Connecticut Children's Medical Center)

14:00 - 15:30 **Lunch**

Main Room

- 16:00–16:45** **Presentation:** Cell-gene therapy using lentiviral vectors for Pompe disease by **Dr. Pilar Muñoz** (The Pfizer Center-University of Granada-Junta de Andalucía of Genomics and Oncology Research, GENYO)
- 16:45-17:30** **Presentation:** Respiratory involvement of Pompe disease by **Dr. Barbara Smith** (University of Florida)

- 17:30-18:15** **Presentation:** Research utility to improve the quality of life in the **McArdle** disease by **Dr. Alfredo Santalla** (University of Pablo de Olavide)

Multipurpose Room

- 16:00-17:00** **Presentation:** Rare diseases in schools by Ms. **Isabel Moráis**
- 17:00–19:45** Presentation on Hepatic GSD disease by **Dr. María José de Castro**
- 19:45–20:20** Evaluations to Hepatic GSD, type 3 patients

- 20:20–21:00** Evaluations to Hepatic GSD, type 4, 6 and 9 patients
- 18:15-19:00** **Presentation:** Study of McArdle disease carriers by **Dr. Judit Nuñez** (Hospital German Trias I Pujol, Barcelona)
- 19:00–21:00** **AEEG Assembly**

21:00 - 22:30 Dinner

Sunday 14 October

Activities of the IX Congress

09:00 - 11:00 Meeting of the AEEG Governing Board

Multipurpose Room

9:00– 10:30 Evaluations to new patients with Hepatic GSDs

10:30–12:00 Doubts from associates affected by Hepatic GSDs

Organized by:



Sponsored by:



Contributors:



